

12-17-2016

“Welcome to the Real World” Inclusive Research with People with Learning Disabilities: A Doctoral Journey

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Recommended APA Citation

Durell, S. (2016). “Welcome to the Real World” Inclusive Research with People with Learning Disabilities: A Doctoral Journey. *The Qualitative Report*, 21(12), 2308-2330. Retrieved from <https://nsuworks.nova.edu/tqr/vol21/iss12/9>

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Abstract

Many people with learning disabilities have been and are still been excluded from an active involvement in research. In the UK, this position has been challenged by people with learning disabilities, their supporters and academic allies, through the advancement of inclusive research. But calls have been made for a clarification of the roles that can be played by these research supporters and researchers, to expose asymmetrical relations and to advance existing practices, as well as to develop a better understanding of quality in inclusive research. In response to these matters, this paper offers an account of the experiences of a nondisabled doctoral researcher of “doing” inclusive research with people with learning disabilities. It will present critical insights into inclusive ways of doing research from a learning disability perspective, while offering data that is of relevance to researchers working beyond the field of learning disabilities and seeking the active participation of different groups in the research process. Consequently, people whose first language is not research can have a say in the production of knowledge and they can be credited not only as members of research communities but also of their societies.

Keywords

Focus Groups, Inclusive Research, Learning Disabilities, Nondisabled Supporters, Research Advisory Group

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Acknowledgements

I would like to thank members of this PhD study’s research advisory group and focus groups for sharing their experiences and expertise with me. I am also extremely grateful to Pepsi for all of their support and for welcoming me “to the real world”. So, I would also like to credit them for the subtitle of this paper. The fieldwork research on which this paper was part of a doctoral study that was funded by the Faculty of Health and Life Sciences, Coventry University (United Kingdom).

“Welcome to the Real World” Inclusive Research with People with Learning Disabilities: A Doctoral Journey

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Many people with learning disabilities have been and are still been excluded from an active involvement in research. In the UK, this position has been challenged by people with learning disabilities, their supporters and academic allies, through the advancement of inclusive research. But calls have been made for a clarification of the roles that can be played by these research supporters and researchers, to expose asymmetrical relations and to advance existing practices, as well as to develop a better understanding of quality in inclusive research. In response to these matters, this paper offers an account of the experiences of a nondisabled doctoral researcher of “doing” inclusive research with people with learning disabilities. It will present critical insights into inclusive ways of doing research from a learning disability perspective, while offering data that is of relevance to researchers working beyond the field of learning disabilities and seeking the active participation of different groups in the research process. Consequently, people whose first language is not research can have a say in the production of knowledge and they can be credited not only as members of research communities but also of their societies. Keywords: Focus Groups, Inclusive Research, Learning Disabilities, Nondisabled Supporters, Research Advisory Group

As a result of an intricate range of cultural, economic and social factors, contributions by people with learning disabilities to the production of knowledge have been at best marginalised and at worst rendered silent. Indeed, many people with learning disabilities have been and are still been excluded from an active involvement in research (e.g., Townson et al., 2004). In the United Kingdom (UK), this position has been increasingly challenged by self advocacy groups of people with learning disabilities and their academic allies, through the advancement of inclusive research (Johnson, 2009). Nind (2014a) emphasises how “inclusive research acts critically on the relationship between those who research and those who are researched to make the research more collaborative and relevant” (p. 525). Calls have therefore been made for a clarification of the roles that can be played by nondisabled researchers and research supporters, so that asymmetrical relations between them and people with learning disabilities can be exposed and inclusive research practices can be developed further (e.g., Walmsley, 2004; Williams et al., 2005); together with a better understanding of quality in inclusive research (Nind, 2012).

In response to these matters and through this paper, I offer an account of my doctoral experiences of applying inclusive principles to research with people with learning disabilities, as a nondisabled researcher (Durell, 2013). While it will present critical insights into inclusive ways of doing research from a learning disability perspective, it can still offer data that is of relevance to researchers working beyond the field of learning disabilities and seeking the active participation of different groups in the research process. Consequently, people whose first language is not research can have a say in the production of knowledge and they can be credited not only as members of research communities but also of their societies.

First, I will introduce the term “learning disabilities” and how it is defined by international and national organisations and by people with learning disabilities and their

associations in the UK. I will then turn to the concept of an inclusive approach to research with people with learning disabilities. This will be followed by an overview of my PhD study and the aims and objectives of this research. I will also present an outline of this study's research advisory group and focus groups which will include the aims of the groups, the accessible materials that were designed and developed for prospective group members, the recruitment process, their membership and the general format of the meetings. I will then focus on the contributions of the nondisabled research supporters to the groups' activities and to the facilitation in the co-production of knowledge by members with learning disabilities. Where applicable, I will attribute a pseudonym or name initials to each quotation or idea from a research advisory group or focus group member to the appropriate individual, with the intention of maintaining their anonymity from the reader. Finally, I will conclude by reiterating how through the translation of inclusive research principles, people with learning disabilities can have a say in the knowledge production process.

Learning Disabilities: Terminology and Applications

In the UK, the term "learning disabilities" is commonly applied within health and social care policy, practices and provision. But many people with learning disabilities and their self advocacy groups favour the phrase "learning difficulties" which is a term that is also generally used within educational settings and refers to people with specific learning difficulties such as, dyslexia (Gates & Mafuba, 2016).

Learning disabilities replaced previous terms that are now perceived as derogatory and obsolete, such as "mental handicap," "mental retardation," "mental subnormality" and "mental deficiency." Other terminologies are used in other countries and at an international level, like for instance, "intellectual disabilities." They all refer to the same range of impairments but have different connotations (Emerson et al., 2001).

The application of learning disabilities as a concept can vary according to the context in which it is used and it is a term that is relatively difficult to define, with many different definitions presently in use (MacIntyre, 2008). For example, the World Health Organisation (2016) lists "learning disabilities" as "mental retardation" within the *International Classification of Diseases* (ICD-10), under the mental and behavioural disorders section. It defines it as "a condition of an arrested or incomplete development of mind" and assesses the measure of learning disabilities via intelligence quotient (IQ) testing and other social adaptation assessments.

Another definition of the term learning disabilities was presented in the UK, by the Department of Health (DH) in 2001, through the White Paper: *Valuing People*. This report is based on the premise that people with learning disabilities have legal and civil rights, should have the opportunity to be independent and be able to make choices in their everyday lives and should be fully included in their local communities (pp. 23-24). Learning disabilities is observed to include the presence of "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development" (p. 14).

This definition includes people with a diverse range of impairments, including physical and/or sensory and the presence of a low IQ does not necessarily justify health and social care provision. Social functioning and communication skills assessments are also encouraged for determining need. But clear distinctions are given in relation to people with learning disabilities and autism and the exclusion of people with a higher level autistic spectrum disorder, such as Asperger's syndrome is asserted, as are individuals identified as having "learning difficulties" and supported within educational settings (pp. 14-15). A new strategy: *Valuing People Now*

(DH, 2009) superseded this publication but the underlying principles and the definition of learning disabilities of its precursor remains.

However, Boxall et al. (2004) identify the DH's (2001) definition as inadequate because it implies that learning disabilities is an inert problem that is located within the person and ignores the array of "political, social, environmental and cultural influences," including segregational policies and the attitudes and expectations of others, which can impinge upon our ability to learn (p. 110). Walmsley (2005) observes that *Valuing People* (DH, 2001) "sits in a solitary place" misaligned from legislation that was prompted by disabled people's movements and much influenced by normalisation theory and social role valorisation principles (p. 725).

Normalisation and social role valorisation principles

In brief, the principle of normalisation regards people with learning disabilities as undervalued by society and who possess "stigmatised identities," with second rate services reinforcing a "vicious circle of devalued identities." Its application to the transformation of "high quality services" can generate "high quality lifestyles" for people with learning disabilities, enabling their integration with socially valued individuals. However, this promotion of associations between people with learning disabilities and individuals ascribed with a "high social value," namely nondisabled people, has been noted as a matter of concern. Such line of reasoning can have serious implications for the relationships between people with learning disabilities and the identification of other people with learning disabilities, "as the problem to be avoided (literally), undermines the possibility of collective political action, based on commonality of experience" (Chappell, 1997, pp. 46 - 49).

The rise of normalisation principles which developed during the 1960s and 1970s in Scandinavia (e.g., Bank-Mikkelsen, 1980; Nirje, 1980) and in America (e.g., Wolfensberger, 1972) were a major influence on the development of services for people with learning disabilities in the UK. The latter version was adopted during the 1970s and 1980s by service providers and academics "who were concerned at the poor standards of care in many long stay hospitals" (Chappell, 1999, pp. 103-104). Wolfensberger (1972) took normalisation principles further, reframing them as social role valorisation (Johnson et al., 2010). But while many professionals have been influenced by the principle of normalisation, it has not been adopted as an underlying philosophy by disabled people or by organisations, which are accountable to them (Oliver, 1999a).

The social model of disability

It is also important to mention the social model of disability as another key influence to the development of modern-day discourses of learning disabilities (Gates & Mafuba, 2016).

The origins of the social model stems from a publication by the Union of the Physically Impaired Against Segregation (UPIAS, 1976). This document radicalised the meaning of disability with a revolutionary definition, stating that impairment was not the main cause of the social exclusion experienced by disabled people "but in the way society responded to people with impairments" (Oliver, 2009, pp. 42-43). In the UK, UPIAS was at the front line of disabled activists and their organisations and their increasing criticisms of the individual model of disability and the call for an alternative approach (Barnes et al., 2010).

The individual model has dominated Western societies' view of disability, since the late eighteenth century (Barnes, 2009). It places the disability "problem" within the individual and deems the causes of this "problem" as developing from the functional restrictions or psychological losses that are presumed to arise from disability (Oliver, 1996). Once the person is classified in this manner the "disability" becomes their defining feature and their inability is

generalised. The solution then lies in intervention by doctors and allied professionals applying curative and rehabilitation practices, with these “experts” defining the individual’s needs and how they should be met. Further, the aim of this medicalisation of disability is to overcome or minimise the negative consequences of the impairment: a personal tragedy, which dictates that life should be led as a passive victim, dependant on family and friends, welfare benefits and services (Barnes et al., 2010, p. 161).

By contrast, from a social model perspective, disability is associated with “disabling barriers and attitudes” and the focus is redirected from medical conditions and functional limitations to “the physical, social and economic disabling barriers experienced by disabled people and the impact of anti-discrimination policies.” It does not deny the significance of impairment in people’s lives or the relevance of medical treatment to the experience of impairment. But it emphasises the indifference by supporters of an individual approach to the existence or influences of “disabling social and environmental barriers” (Barnes & Mercer, 2006, pp. 36-37).

Since the 1970s and the 1980s, the social model has been a significant medium for the growing politicisation of disabled people and their associations worldwide, which has influenced social policy globally (Barnes, 2000). By the 1990s, it was also adopted by professionals and became incorporated into the state (Oliver, 2009).

Nevertheless, the social model has not been without its critics, from within and beyond the disabled people’s movement and disability studies (Barnes & Mercer, 2010; Thomas, 2007). An uneasy relationship between the disabled people’s movement and people with learning disabilities has also been observed, with few people within learning disability circles initially appreciating the influential significance of disability studies (Walmsley, 2005). Further, the marginalisation of people with learning disabilities by the social model and their exclusion from discourses on the sociology of disability has been noted (Chappell, 1998). But this exclusion may be explained by the relative lack of publications that have applied the social model to the experiences of people with learning disabilities rather than weaknesses in the explanatory power of the approach itself. Generally, the majority of social model writings have been created by disabled people without the learning disabilities label, who have not necessarily sought to portray the experiences of people with learning disabilities. But “this is perhaps not surprising, given the emphasis of the disabled people’s movement on self-representation and disabled people speaking on their own behalf” (Boxall, 2002, pp. 217-218). Moreover, people with learning disabilities may already be “doing” the social model, although not in written form or articulated in theoretical language, like for example, through self advocacy groups of people with learning disabilities (Chappell et al., 2001, pp. 48-49).

People with learning disabilities and self advocacy

In the UK, self advocacy groups of people with learning disabilities appeared to have originated in 1984, through London Boroughs’ People First. While an array of service based groups and independent groups emerged, the latter type was deemed as superior as they employed their own support and were less affiliated to a service system. This arrangement reflected citizen advocacy principles and influenced thinking on self advocacy. However, the development of a national self advocacy organisation has been impeded by the somewhat informal arrangement of local groups. Still, distinct and at times, competing constructions of self advocacy have been identified. These include self-advocacy as a way for people to speak up and out and assert identity; and self advocacy as a vehicle for a collective movement that represents the interests of a particular group (Buchanan & Walmsley, 2006). Goodley (2000) argues that the self advocacy movement has encouraged people with learning disabilities “to

revolt against disablement in a variety of ways, in a number of contexts, individually and collectively, with and without the support of others” (p. 3).

Self definition has also been identified as a major feature of the organisation of disabled people (Campbell & Oliver, 1996). Equally for people with learning disabilities, self advocacy can present a framework for re-examining old terminology and for developing new ones (Chappell, et al., 2001):

I prefer the term learning difficulties – it’s a better term. Why is it better? Because it’s much nicer – we want to learn and *I like it*. I got the council to change the name (Lloyd Page (self advocate) cited in Goodley, 2000, p. 85).

Additionally, an understanding of the learning disabilities label can lead to a repossession of disability by people with learning disabilities, in accordance with the social model (Chappell et al., 2001):

Who has 47 cells? I have. They haven’t, they’ve only got 46. (Anya Souza (self advocate) cited in Goodley, 2000, p. 124)

Further, this “sense of collectivity” promoted by self advocacy has been acknowledged as a social approach that can challenge the divisive feature of the categorisation of people into subgroups of impairment and enable individuals to reveal “their self determination in the face of the indignities of discrimination” (Chappell et al., 2001 p. 48).

Boxall (2002) proposes that rather than focusing on the marginalisation of people with learning disabilities by social model discourses, it may be preferable to examine the ways in which they can be supported to contribute to these discussions. So, with facilitated access to participation in academic debate, people with learning disabilities can support disability activism by challenging segregation and by identifying commonalities with other disabled people. This in turn can strengthen the social model of disability (Boxall, 2007).

To label or not to label

In the UK, the terms “learning disabilities” and “learning difficulties” can be applied interchangeably, within health and social care contexts for adults (Holland, 2011). Indeed, debates persist between the self advocacy movement of people with learning disabilities, academics and health and social care professionals with regards to what is the most suitable terminology to apply. This can cause confusion among international academics, clinicians and teachers. Nevertheless, such opinions appear to remain divided for the foreseeable future (Gates & Mafuba, 2016).

But none of this should deny the dilemmas of diagnosing and labelling people with a categorisation of learning disabilities (e.g., Inglis, 2013). Ho (2004) recognises how this diagnostic label can establish service eligibility and protection by civil rights legislation. But it can also impose the individual model of disability by professionals and policy makers onto people with learning disabilities and limitations in educational and social systems can be ignored. Consequently, the definitional control lies with professionals and while a learning disabilities label “can open doors to resources” it can also cause dehumanising treatment and restrict opportunities (Gillman et al., 2000, p. 389). The consequences of this categorisation:

is sometimes more than just being called names. It does sometimes mean that you get the support that you may need. It also means that lots of other things happen to you –

like day centres, and being sent to live in houses you don't like. (Palmer et al., 1999 p. 37)

Inclusive Research with People with Learning Disabilities: An Overview

Nind (2014a) observes that the term inclusive research is still not widely used (p. 526). But in the UK within the field of learning disability, research has been increasingly framed as inclusive and its development has been influenced by people with learning disabilities and their academic allies, through normalisation principles, the social model of disability and the self advocacy movement. While these matters were introduced in an earlier section of this paper, it is still important to place them within the context of inclusive learning disability research.

With regards to normalisation principles, these beliefs underpinned the prerequisite of a humanistic value set, which asserted that the views of people with learning disabilities should be considered in their experiences of everyday life (Gilbert, 2004). This included their inclusion in evaluation and research processes (Walmsley, 2001). So, it paved the way for people with learning disabilities to be taken seriously as potential research respondents, with the assignment of "valued social roles" and "on the duty of nondisabled people to work for the interests of devalued people, particularly as advocates" (Walmsley & Johnson, 2003, p. 59). Normalisation also provided "the conditions to make speaking out possible" and influenced the progression of inclusive research approaches of the late 1980s and early 1990s (Walmsley, 2001, p. 188).

Equally, with the emergence of the social model of disability, some researchers endeavoured to go beyond participatory practices and attempted to meet the more rigorous demands of emancipatory disability research (Walmsley & Johnson, 2003). Consequently,

This raised the stakes considerably in terms of what some learning disability researchers began to demand of themselves and their work. The type of research characteristic of normalisation inspired models – that the research should demonstrate ways in which a "normal life" could be promoted – was not enough. Somehow, the researcher was expected to find ways of giving control to people with learning disabilities, and of being accountable to them. (Walmsley, 2005, p. 734)

Self advocacy also played an important role in the facilitation of inclusive research, as without this movement there would be "no possibility" of organising groups of people with learning disabilities, through which they could work collectively on research projects. Moreover, if researchers are to be accountable to organisations of people with learning disabilities, then self advocacy groups are of the essence and the particular form for "speaking up and out," within learning disability circles (Walmsley & Johnson, 2003, p. 54).

Walmsley (2001) describes "inclusive research" as a less cumbersome umbrella term that refers to a range of research approaches that have been traditionally presented as "participatory" or "emancipatory" and in which people with learning disabilities "are involved as more than just research subjects or respondents" (pp. 187-188). People with learning disabilities are therefore actively engaged "as initiators, doers, writers and disseminators of research" (Walmsley & Johnson 2003, pp. 9-10). Indeed, in their review of the learning disability literature, Bigby et al. (2014a) identified three main approaches to inclusive research with people with learning disabilities; namely, "advisory, leading and controlling, and collaborative group" (p. 3).

Walmsley and Johnson (2003) propose that if a research project is to be perceived as "inclusive," either from a participatory or emancipatory approach, it must exhibit key characteristics. These include that the research problem is one that is owned by disabled

people, though it may not necessarily be initiated by them. The project should advance the interests of disabled people, with nondisabled researchers working for and with people with learning disabilities. It should also be undertaken collaboratively and involve people with learning disabilities, throughout the research process. Additionally, people with learning disabilities should be able to exert some control over processes and outcomes. Further, “the research question, process and reports must be accessible to people with learning disabilities” (pp. 63-64, p. 78)

However, it is essential to differentiate between emancipatory and participatory traditions to disability research and the relations between disabled people and researchers. As Chappell (1999) explains, “in the former, researchers are accountable to the organisations of disabled people; in the latter, the relationship is looser and is based on alliances” (p. 111). Further, emancipatory disability research as developed in the UK by the disabled people’s movement emerged from disabled people’s distrust of mainstream research. Consequently, this research approach took the participation of disabled people “as a necessary but not sufficient condition of research. What was crucial was that research should be concerned with their *liberation*” (Beresford, 2015).

Nind (2014b) observes how the overarching use of the term “inclusive research” has also been extended beyond learning disability circles to incorporate other approaches, such as user-led research, child-led research and democratic dialogue. As a consequence, this extension embraces “a whole family of approaches, all of which reflect a particular turn towards democratisation of the research process” (p. 1). Moreover, and despite the underlying variations in their approach, advocates of inclusive research “focus on collaboration and respect for different ways of knowing and different knowers with an explicit purpose of social transformation” (Nind, 2014a, p. 527).

Indeed, an active involvement in research by people with learning disabilities has led to the growth of “alliances with sympathetic non learning disabled people” (Gilbert, 2004, p.300). As a result, inclusive learning disability research has been identified as more closely associated to participatory rather than emancipatory traditions (Walmsley, 2001). But “working with nondisabled allies is often seen as a watering-down of true emancipatory research” (Williams & England, 2005, p. 30) and while participatory practices have been observed as offering a viable way to the active involvement of people with learning disabilities in research, it can still uphold “the authority of nondisabled researchers and institutionalises the relative power positions of researcher and researched” (Chappell, 1999, pp. 111-112).

Kiernan (1999) argues how from an emancipatory disability research perspective, people with learning disabilities must be genuinely included and be in control throughout all of the stages of the research process. But as research is dependent on learning skills, it can be more inaccessible for people with learning disabilities than it would be for disabled people, who do not experience a “learning” impairment. He thus asserts that people with learning disabilities require considerable support from nondisabled researchers in order to partake in research, raising concerns over the validity of such research as a true portrayal of their views. So, as Williams et al. (2005) argue if most researchers with learning disabilities require some form of support, an exploration of how these practices are managed is of the essence and can highlight how nondisabled supporters can partake in the research process, “without taking it over” (p. 8). Walmsley (2004) also calls for enlightenment on what roles can be played by research supporters, so that current skills can be developed (p. 66); while Nind (2012) emphasises how a better understanding of quality in inclusive research can be captured from the reflective discussions by learning disability researchers of the research process and of the ways of researching together. Consequently, researchers with and without learning disabilities can consolidate further knowledge “about how to conduct research in new, inclusive ways that

are respectful of the agendas, views and needs of people with learning disabilities” (Nind, 2015, p.1).

Inclusive Learning Disability Research: A Doctoral Journey

With these matters in mind, this paper offers an account of my doctoral experiences of applying inclusive principles to research with people with learning disabilities, as a nondisabled researcher (Durell, 2013). I chose to apply the term “inclusive research” as defined by Walmsley and Johnson (2003) because it acknowledges both participatory and emancipatory approaches for research with people with learning disabilities and by so doing, it did not make any prior assumptions about whether this study would correspond specifically to either of these research traditions. It also reflected the origins and values of this style of research (Williams et al., 2005). I did recognise that this study would not meet fundamental emancipatory principles as for example, I was in control of the research and not people with learning disabilities and it therefore would have been better placed in a participatory perspective. But I strived to go beyond participatory practices in facilitating research that could contribute to the emancipatory process of disabled people (Walmsley & Johnson, 2003). Therefore, this study remained open to emancipatory thinking so that the research process was informed and influenced by people with learning disabilities, themselves.

Nevertheless, I approached this doctoral journey with some trepidation, particularly as it would be challenged by the material and social relations of research production. In practice, this study was set within a doctoral framework and this can limit the “inclusiveness” of a project (Bjornsdottir & Svendsdottir, 2008). Zarb (1992) acknowledges that neither disabled people nor researchers “have much control over the material relations of research production;” but he asserts that researchers can still transform the social relations of research production, through their research practices and the associations that they develop with disabled people and their organisations (p. 127). Indeed, I was conscious of how “the established social relations of research production give rise to inequalities of power between researcher and researched” (Priestley, 1997, p. 88). As a nondisabled researcher, one of the key challenges was to ensure that my instigation for analysing the representations of people with learning disabilities by the contemporary, print version of English national newspapers did not risk:

work being done which does not benefit people with learning disabilities, as so much past (and some current) research has done. It is indeed a fine line between acknowledging that people with learning disabilities do not know enough to ask the right questions and giving researchers the sense that they have the right to do whatever research they choose. (Walmsley & Johnson, 2003, p. 140)

However, since at least the 1960s, disabled people and their organisations have been highlighting the relationship between “disablist imagery, the media and discrimination” (Barnes, 1992a, p. 2). In recent years, some people with learning disabilities and their supporters have also successfully challenged disabling media portrayals through regulatory bodies (e.g., Wild Bunch, 2010). But while there is now a growing body of empirical research within the areas of disability and media (e.g., Haller, 2011), there is a significant lack of learning disabilities studies in this area, with little research specifically examining newspaper representations of people with learning disabilities and a near absence of their views and experiences, within this body of work (e.g., Wertheimer, 1987). Consequently, I initiated research in this area primarily because the matter in question could be of concern to people with learning disabilities, if they were made aware of it (Walmsley & Johnson, 2003). Further, as Minkes et al. (1995) emphasise, “most of the time... the very people in whose name the

research is done never get to hear about it” (p. 94). This study therefore incorporated “the idea of research as production” (Oliver, 1999b, p. 183), turning its focus onto the behaviours of oppressors, with the intention that it generated knowledge of use to people with learning disabilities and their supporters in their struggles against oppressive practices (Oliver & Barnes, 2012).

Moreover, the social model of disability informed and influenced the focus of this study. Nevertheless, not all people labelled as “disabled” regard themselves as “disabled or are united on a theoretical and research agenda guided by the social model” (Barnes & Mercer, 2004, p. 9). So, I had to ensure that this approach informed my research practices, rather than impose theory on the experiences of individuals (Bailey, 2004). This reiterated the need for this research to be “reflexive and self critical” (Barnes & Mercer, 2004, p. 9).

The overall aim of my PhD study was to develop critical insights in conducting inclusive research, by adopting a mixed method approach in which people with learning disabilities were placed at the centre of the research process (Durell, 2013). It identified and critically analysed the significance and meanings of representations of adults with learning disabilities by the UK’s contemporary, national newsprint medium by uniquely incorporating distinct but interrelated data collection stages. These included a research advisory group with people with learning disabilities and their supporters; a content analysis of 546 learning disability news stories; two focus groups with people with learning disabilities and their supporters; and a researcher’s diary.

For the purpose of this paper, I will be focusing on the research advisory group and focus groups stages of this study, while incorporating my reflections of the research process. I will now present an outline of the aims of the groups, the accessible materials that were designed and developed for prospective group members, the recruitment process, the groups’ membership and the general format of the meetings.

The Research Advisory Group: Underlying Aims

Tarleton et al. (2004) identify “advisory or consultative groups” as one of the main ways in which people with learning disabilities “are involved in research” (p. 75). The Learning Difficulties Research Team (2006) found that in their review of twelve learning disability research projects “all but one” involved advisory groups. These researchers concluded that

advisory groups are better at involvement when they meet regularly, are personal and friendly, have social time together, include more people with learning difficulties, pay people (*and*) find more creative ways of discussing issues, asking questions and speaking up. (p. 63)

This study’s research advisory group was set up after ethical clearance had been granted by my University’s Research Ethics Committee and I could proceed with its development. It was therefore not convened in time to inform the study’s overall research design. However, subsequent fieldwork practices were informed and influenced by the research advisory group, as it ran concurrently with the other data collection stages of the study.

Three main aims underpinned the setup of this group. First, it supported the engagement of people with learning disabilities in the co-production of knowledge, as active members of research communities and by doing so, members were able to exert some direction over the process and outcomes of this study, corresponding with inclusive research principles (Walmsley & Johnson, 2003). Parallel aims have underpinned the setting up of research advisory groups in other learning disability research studies (e.g., Bigby et al., 2014a; Porter et al., 2006).

The second aim of the research advisory group concerned my optimistic endeavours to go beyond participatory research practices with the intention that involvement in this group's activities could in some way contribute towards the emancipatory process of its members (Walmsley & Johnson, 2003). For example, Rodgers (1999) convened a group for her study which involved professionals, carers and women with learning disabilities, committing herself to supporting the group "to develop for its own needs, as well as using it as a sounding board for" her ideas (p. 423). However, "research cannot ever lead directly to the empowerment of disabled people... empowerment is not something that can be given, but something that people must take for themselves" (Zarb, 2003, p.8). The central issue "is not how to empower people but, once people have decided to empower themselves, precisely what research can do to facilitate this process" (Oliver, 1992, p. 111).

Finally, the research advisory group offered me ongoing contact with people with learning disabilities and their supporters. These interactions exposed me to the views and experiences of (some) people with learning disabilities and kept me informed on related learning disability matters. Indeed, Barnes (1992b) asserts that in order "for researchers, with or without impairments, to gain a comprehensive understanding of the meaning of disability it is essential that they interact with disabled people on a regular basis" (p. 122).

The Focus Groups: Underlying Aims

These three main aims also applied to the focus groups of this study. However, one central objective underpinned the use of this data collection method, namely "the idea of research as production" (Oliver, 1999b, p. 183). By turning the focus onto the behaviours of oppressors, it aimed to generate knowledge that could be of use to people with learning disabilities and their supporters in their struggles against oppressive practices (Oliver & Barnes, 2012).

An analysis of media content can draw attention to a variety of themes that require further examination through focus group discussions, like in audience reception studies (Bryman, 2008). But I was mostly concerned in applying the findings of this study's content analysis, as a basis for subsequent critical analyses by people with learning disabilities and their supporters of contemporary representations of adults with learning disabilities by the print version of English national newspapers, to facilitate their active engagement in disability and media research discourses, as co-producers of knowledge.

As previously highlighted in this paper, there are few learning disability studies within the field of disability and media with few studies examining the newspaper representations of people with learning disabilities and a near absence of their views and experiences in this body of work (e.g., Haller, 2011). So, I instigated this research because it could be of interest to people with learning disabilities, if they were made aware of it (Walmsley & Johnson, 2003).

The incorporation of focus groups in this study's overall research design could support such intentions, mainly as they can be perceived as a "friendly, respectful research method" and for focus group members, this can involve "both an enjoyable set of interactions and a sense of being listened to" (Morgan, 1998, p. 59). Still, it would have been naive of me to assume that such exchanges would reflect everyday conversations. Instead, as Kitzinger (1994) proposes, focus groups: "should be used to encourage people to engage with one another, verbally formulate their ideas and draw out the cognitive structures which previously have been unarticulated" (p. 106).

Moreover, I wanted to go beyond participatory research, as specified by the second aim of this study's research advisory group so that involvement in a focus group could be in some way contribute to the emancipation of its members (Walmsley & Johnson, 2003). The focus group stage of this study was centred on supporting the facilitation of such a process.

Accessible Materials for Prospective Group Members

While acknowledging that people with learning disabilities “are a heterogeneous group and the needs of people who bear this label vary greatly” (Townasley et al., 2003, p. 40), the written medium has been identified as a barrier to the participation of many people with learning disabilities in academic discourses. However, these discussions could be made more accessible with some support and creativity (e.g., Docherty et al., 2005). Further, as Cameron and Murphy (2006) emphasise the provision of “accessible and understandable information is a significant part of the recruitment and consent process” (p. 116). Moreover, accessibility is of the essence for inclusive learning disability research (Walmsley, 2001).

With these principles in mind, I produced a range of proforma for prospective group associates. They were used by all members because distinct versions for disabled and nondisabled people could have perpetuated “what amounts to a “them” and “us” ethos” (Bashford et al., 1995, p. 213). These included various proforma such as, an information sheet, a frequently asked questions page and a consent form. Diverse resources informed their development. For instance, I examined information leaflets from past research studies (e.g., the Learning Difficulties Research Team, 2006) and varied guides for making information more accessible (e.g., Inspired Services, 2004). Additionally, the development of these initial documents was supported through consultations with members of my doctoral supervisory team and former fellow colleagues (e.g., Brady, 2004). These original forms also needed to be “tested for effectiveness by direct consultation with the target audience” (Townasley et al., 2003, p. 390). They were therefore reviewed by research advisory group members and amended accordingly, once this group was set up and running.

Bashford et al. (1995) observe how illustrations can be “a vital source of extra information and may well serve as the main source of meaning for some readers” (p. 217). Images for the materials were sourced from version three of Photosymbols (2016), a picture library for making Easy Read information for people with learning disabilities. Additionally, a photograph of me was positioned next to my contact details, so that individuals could add a face to the name (e.g., Ham et al., 2004). This was accompanied by a picture of several English national newspapers to support the association of this study with the newspaper medium.

The details of the information sheet were also transcribed to an oversized paper roll design, which presents with a combination of pictures and words, information in an easy to understand format. This is a popular communication tool that is applied within learning disability circles, including self advocacy groups of people with learning disabilities (e.g., Talkback, 2016). While the paper roll was employed throughout the life course of the research advisory group to reiterate information, to support discussions and to maintain consent as an ongoing process, during the focus group meetings, it was mostly used during the introductory part of the sessions.

The paper roll was also photographed in consecutive sections. These images were incorporated within an A4 landscape word document and were distributed to potential group members, as per the text based information sheet. Individuals therefore had access to both a pictorial edition of the information sheet and the original document. This reflected the underlying principle of “parallel texts,” which is a way of presenting information to people with learning disabilities in an accessible format and “not only provides a simplified version but also facilitates access to the main document” (Bashford et al., 1995, p. 211).

Nevertheless, as Bashford et al. (1995, p. 219) observe “making documents accessible is only one aspect of the proper involvement of people with intellectual disabilities in research.” Indeed, close attention should also be given to other matters during the development and the facilitation of inclusive research practices. For example, Booth and Booth (1996) identify a range of inhibiting factors which can limit some people’s ability to converse openly within

narrative research. This includes “inarticulateness, unresponsiveness, a concrete frame of reference and difficulties with the concept of time” (p. 55). However, they insist that researchers should place more emphasis on how to overcome the barriers that can impede the involvement of people with learning disabilities in research rather than focus on their “limitations.” Indeed, this study was underpinned by a responsive approach to the facilitation of inclusive research practices so that the individual requirements of group members could be accommodated. Further, the research advisory group could provide this study with the expertise for the development of resources and processes that could enhance the research experiences of focus group members.

The Recruitment Process of Group Members

Since this study was set within a doctoral framework, I knew that I would be working to a tight timetable. So, in order to speed up the recruitment process, I mostly identified prospective members of the research advisory group and the focus groups through initial contacts with senior managers with whom I had previously engaged with professionally from a range of learning disability organisations. In addition, I identified prospective focus group members through my learning disability networks, as I found an association involved in media related matters with people with learning disabilities. So, I approached a manager from this organisation not only because the subject matter of this study could be of interest to them but because the resultant findings of its content analysis could prove useful for people with learning disabilities and their supporters, in their struggles against oppressive practices (Oliver & Barnes, 2012).

Collectively, these key stakeholders were provided with the aims and objectives of the study, its approach and an overview of what individuals could expect in terms of their involvement in the project. They were also informed of this study’s eligibility criteria with regard to the prospective members of the research advisory group and the focus groups, including supporters of people with learning disabilities. These included an expectation that they would identify their primary role as a supporter for a member or members of the research advisory group or focus groups. Indeed, Nind and Vinha (2013a) emphasise that while the roles that can be played by support staff or academic researchers of inclusive research with people with learning disabilities have been identified as essential for the smooth running of these projects, clarity is still needed about the prerequisites of these research supporters.

Nevertheless, nondisabled research supporters were included in this study because prospective group members with learning disabilities may have wanted someone, who they knew and trusted to be present at the meetings for support. For example, the Learning Difficulties Research Team (2006) allowed supporters into their interviews with people with learning disabilities if individuals “wanted them there” (p. 32). Walmsley (2004) also observes how many people with learning disabilities “need support to lead fulfilling lives, including participation in research” (p. 66). Moreover, as this study was underpinned by inclusive research principles, all group members were considered as prospective co-researchers. This involves an exploration of a person’s “potential for decision making and participation in research activity” (Stevenson, 2010, p. 45).

This study therefore remained open to contributions from nondominating supporters (Tarleton et al., 2004) and throughout the lifespan of the groups I encouraged a teamwork approach between disabled and nondisabled members, because as observed by other learning disability researchers, everyone can learn from each other (e.g., Bigby et al., 2014b; Williams et al., 2005). Further, as Nind and Vinha (2013b) observes we can try “to avoid the tyranny of who was the real expert and instead position everyone as knowers and learners” (p. 22). However and in contrast to other learning disability studies (e.g., Butler et al., 2012), I did not

experience any gate keeping problems during the recruitment process of group members for this study.

Influenced by the ethical standards of other learning disability researchers (e.g., the Learning Difficulties Research Team, 2006), the capacity to give informed consent was negotiated with the individual, rather than by proxy. Potential group members were given the option to sign a consent form or to assert their consent and this was recorded by their supporters on the said proforma. So, consent could be communicated verbally or nonverbally and with or without a signature on a consent form.

Additionally, throughout my fieldwork practices, I approached consent as an ongoing activity. Knox et al. (2000) perceived “informed consent as a process, rather than an initial agreement” and their study’s informant consent form was used simply as a preliminary guide. They argued that it was “the strategy of ‘ongoing consent’ that offered both the informant and the inquirer the opportunity to not only consent to, but also to contribute to the topics of discussion” (pp. 56-57). Rodgers (1999) also acknowledged the use of a “simplified consent form... to mark a participant’s formal decision to take part in” her study and was also aware of how individuals could change their minds, during any of the other stages of the research process. She maintained ongoing consent by providing “information in small doses” and by recapping and repeating particulars, “allowing plenty of time for thought and questions” (p. 428).

Research Advisory Group: Membership and Meetings

The research advisory group of this study had ten members: four women and six men. Their ages ranged from 35 to 65 years and all identified as White British. Two of the members were nondisabled supporters who worked for the day service in which the group was set. Pepsi was the pseudonym chosen collectively by members for the senior support worker who assisted throughout the development and the facilitation of the group. The other support worker left their employment during the life course of the group and was not involved in its latter stages.

The research advisory group was already meeting on a weekly basis in the afternoon for three hours. They had a fortnightly routine when they would meet one week with a self advocacy organisation, with varied agendas running throughout the year. During the other weeks, they were supported by Pepsi and another support worker from the day service and generally these meetings had no set programme. These were the proposed times for scheduling research advisory group activities and as I was familiar with the setup of the day provision and the ways in which this group of individuals arranged their meetings, the group was developed around the schedule of the organisation and meetings were arranged in a manner that was familiar and amenable to its members. This minimised my imposition to the service and to the routines of individuals and staff.

We met on fourteen occasions, over a period of eighteen months and meetings were held within day service premises and arranged through Pepsi. Generally, attendance was good with the occasional apology from members as they were busy elsewhere within the service or away on holiday. With the exception of our fifth session when we only talked for around half an hour after a scheduled self advocacy meeting, I met with the group throughout the weeks that had no set programme and remained with them for around three hours. However, this time slot was not exclusive to research advisory group activities and we always had time for refreshments and gradually integrated other group interests. I thoroughly enjoyed being in the company of group members and engaging with them in these more social pursuits and had always thought that it would have been disrespectful of me, if I had left the meetings once our research advisory group work had been completed.

These interactions also kept me in regular contact with the experiences of people with learning disabilities and their supporters which as formerly mentioned, was one of the main aims of the research advisory group.

Focus Groups: Membership and Meetings

Two focus groups were arranged for this study and altogether, they included eight women and nine men. The first included two managers from a learning disability association that were involved in media related matters with and for people with learning disabilities and five of their colleagues with learning disabilities. The ages of these focus group members ranged from 27 to 60 years with five people identified as White British, one person as Black British and another member as Asian British. This meeting was set up as a one off endeavour and was held within one of their offices. The second focus group involved two project co-ordinators from a learning disability organisation, who were already professionally acquainted with me and eight people with learning disabilities. The ages of these members ranged from 25 to 55 years, all identified as White British. This meeting was arranged around the group's regular session and was held within their customary venue.

While the focus groups were facilitated in a relaxed and accessible manner, allowing members with the flexibility of articulating their views "in their own 'language' and on their own terms," I still applied some structure to the meetings, so that emerging discussions remained focused on the matter in question. The application of such a framework also increased consistency throughout the facilitation of the two focus groups, enabling comparisons between them (Hansen et al., 1998, pp. 273-274). These meetings lasted for around three hours and included a comfort break.

Having presented an outline of the research advisory group and focus groups of this doctoral study, I will now turn to the contributions of the nondisabled research supporters to the groups' activities and to the facilitation in the co-production of knowledge by members with learning disabilities.

Nondisabled Research Supporters: Facilitating the Co-Production of Knowledge

As highlighted earlier in this paper, nondisabled research supporters were included as prospective group members because associates with learning disabilities may have wanted support at the meetings, from someone who they knew and trusted. Moreover, as Seale et al. (2015) observe: "Support workers play an important role in enabling people with learning disabilities to participate in research (for example through facilitating travel to and from research meetings or using advocacy principles and practices to encourage contribution)" (p. 487).

However, this involvement needed to be carefully managed so that they could contribute to the research process, "without taking it over" (Williams et al., 2005, p. 8). Equally, the promotion of a teamwork approach could also enable members to learn from each other (e.g., Chapman & McNulty, 2004).

The research advisory group

With regards to the research advisory group, it proved easy to apply such underlying principles to the general format of the group. Members with learning disabilities wanted someone like Pepsi present in their meetings and unlike other research advisory groups (e.g., Porter et al., 2006) members never opted to attend meetings on their own. Indeed, during the lifespan of the group we compiled ten top tips for researchers who want to work inclusively

with people with learning disabilities (Durell, 2015) and members emphasised the need for researchers to involve everyone and this included staff, who knew them well. Chapman and McNulty (2004) noted how their research group had always said that they “did want support and felt annoyed that other groups did not seem to recognise that as their own choice” (p. 80). So, perhaps as Williams et al. (2005) argue:

it is theoretically possible for people to be in control, but with support. This is a direct parallel with the argument of disabled writers... that independence in general does not mean managing on your own without support. (p. 8)

Teamwork principles were also listed as an important factor by the research advisory group in their ten top tips, as in “helping each other out.” The Learning Difficulties Research Team (2006) asserted that if their project worked, “then it was because of team work” and one significant aspect of this was to “use people’s strengths and talents” (p. 91). Throughout the lifetime of this study’s research advisory group, I observed that working as a team appeared to be of second nature to the group and during meetings, members would support each other in varied ways, such as taking it in turn to read documents aloud for the benefit of those who found reading difficult. However, this team work ethos extended to all members and enabled the group to learn from each other. Naturally this included me, as one member (AM) asserted during a latter discussion: “*Shirley* has learnt from us!”

Further, during our initial discussions when the research advisory group was developing a description of the group, Pepsi identified themselves as part of the group and did not want to be referred to by their job title. Generally, both Pepsi and their colleague enjoyed a reciprocal relationship with members and contributed to discussions in a nondominating manner. So, as Chapman and McNulty (2004) explained about the way of working of their research group, this study’s research advisory group appeared to:

work in a more cooperative manner where everyone is equal rather than to a “people first” model where supporters are in the background and not supposed to take part in things. (p. 78)

However, unlike Butler et al. (2012) who established that during their focus group meetings with people with learning disabilities, “support workers chipping in with their opinions were rarely helpful” (p. 141), in this study the views of nondisabled research supporters were useful to the group and to subsequent fieldwork practices. This can be clearly demonstrated by Pepsi’s feedback on the draft consent form that I presented to the group, at our first meeting. With this information, I was able to produce a document that was more user-friendly not only for the research advisory group but also for prospective focus group members. Pepsi and their colleague also supported the group with the completion of said proforma and the initiation of this study’s ongoing consent process (e.g., Knox et al., 2000).

There were also many other occasions during the research advisory group meetings when Pepsi and their colleague assisted with the facilitation of discussions, such as the reiteration of important information at our first group meeting. They also rephrased questions so that members could have a better understanding of the subject under discussion or they would clarify particular points that were raised by members, when I found dialogues difficult to understand (Llewellyn, 2009).

Additionally, Pepsi and their colleague played a vital role with the practical arrangements of the group. This was of particular significance to this study as it was not only set within a tight doctoral schedule but I also had limited resources at my disposal. Other learning disability researchers have also drawn attention to the impact of practicalities such as

transport and individual support, to the active involvement of people with learning disabilities in research (e.g., Burke et al., 2003; Cambridge & McCarthy, 2001).

Nonetheless, it could be argued that as the research advisory group was set within a day service and its meetings were integrated within a regular slot of this provision, Pepsi and their colleague were just fulfilling their everyday responsibilities by supporting the group with research advisory group activities. However, they always ensured that members were well supported and that meetings ran smoothly. So, for example, meeting dates were arranged via Pepsi who would always check for any prior arrangements in the day services diary, confirming the availability of members, staff and rooms and would advise me accordingly. Moreover, and in their own time, Pepsi reviewed and commented on the initial draft of a methodology chapter of my PhD thesis and reflected on their involvement in this research project, demonstrating an ongoing commitment to the research advisory group that went beyond the lifetime of the group.

The focus groups

Equally, the assistance of nondisabled members was of the essence in the focus group stage of this study and they played a range of significant roles. For example, the recruitment of prospective focus group members was a relatively straightforward process, since it was enabled by research supporters who approached such intermediary responsibilities with enthusiasm and in an open-minded manner. Their associations with the members with learning disabilities of this study's focus groups appeared to have developed "from a place of learning" (Chapman & McNulty, 2004, p. 81). Consequently, I did not encounter any concerns regarding gate keeping during these preliminary communications, as observed by other learning disability researchers (e.g., Butler et al., 2012). Instead, nondisabled members perceived the potential contributions of people with learning disabilities as central to this study, given that they had "great things to say" (GM, second focus group member).

Additionally, I found that focus group members enjoyed a reciprocal relationship with each other and interactions were overtly positive, with research supporters contributing to discussions in a nondominating manner (Tarleton et al., 2004). So, not unlike the research advisory group of this study, focus group associates appeared to be working together as equals, rather than in a manner where research supporters remain in the background and are not expected to participate in discussions (Chapman & McNulty, 2004).

Contributions from nondisabled members also proved useful to the groups' discussions and to my fieldwork practices. This can be clearly demonstrated by an issue that was raised by one of the project co-ordinators (GM) during the second session, with a question that I posed on the total number of learning disability stories that I had found during the content analysis stage of this study and how I needed to put this information into some form of context to the group. Further, on one occasion when I inadvertently found myself unable to hold back on my personal opinion, this research supporter brought this matter to my attention. Subsequently, I was careful not to express my own thoughts during the facilitation of latter discussions.

During the course of the focus groups, there were many occasions when nondisabled members also assumed the informal role of assistant moderator (Krueger, 1994). So, for instance, they readily led on the practical arrangements of the sessions by procuring meeting spaces and varied equipment and by supporting me with the setting up of the rooms. They also provided members with learning disabilities with individual assistance, as and when this was requested or required, including support with the completion of the consent form. Further, research supporters ensured the smooth running of the meetings by clarifying particular points that were raised by members, when I found dialogues difficult to understand (Llewellyn, 2009), encouraging conversations between themselves, as opposed to continuously addressing all comments to me (Owen, 2001). Barr et al. (2003) observed from their focus group study, that

such interactions can promote deeper discussions and they can facilitate “the volunteering of personal views about participants’ individual circumstances that, without the active support and encouragement from their peers, may not have been voiced” (pp. 583-584).

Moreover, as Krueger (1994) explains the assistant moderator can play a key role in subsequent analyses of the session. Within the context of this study’s focus groups, while individuals were only obliged to attend one meeting, nondisabled members went beyond such obligations and facilitated additional feedback from their associates, following the sessions. Indeed, these further commentaries proved to be of the essence in the evaluation of the meetings by members, while revealing a key feature of inclusive research practices (Walmsley & Johnson, 2003) and supporting this study’s underlying principle of “research as production” (Oliver, 1999b, p. 183). They were also of great value, during the subsequent analyses of empirical data.

Conclusion

This paper presented an account of the experiences of a nondisabled doctoral researcher of “doing” inclusive research with people with learning disabilities. It included an overview of my study and the aims and objectives of this research, which was followed by an outline of its research advisory group and focus groups. It then focused on the contributions of the nondisabled research supporters to the groups’ activities. Such committed assistance was identified as of the essence in facilitating the active engagement of people with learning disabilities in the research process, as co-producers of knowledge and the translation of inclusive research principles. Without their continued enthusiasm and support, it would have proved difficult for me to manage, develop and sustain such endeavours, particularly as it was set within a tight PhD schedule and with limited resources. Moreover, group members enjoyed reciprocal relations and worked together as equals, instead of in the traditional manner where research supporters remain in the background and are not expected to play a part in things. As a result, a team work approach enabled group members to learn from each other and as one person pointed out during a research advisory group meeting (AM), this included me! Consequently, the translation of inclusive research principles can present ways for giving people whose first language is not research, a say in the production of knowledge, crediting them not only as active members of research communities but also of their societies. Because as this RAG member asserted further: “what do university people know about learning difficulties?”

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I would like to thank members of this PhD study's research advisory group and focus groups for sharing their experiences and expertise with me. I am also extremely grateful to Pepsi for all of their support and for welcoming me "to the real world." So, I would also like to credit them for the subtitle of this paper.

The fieldwork research on which this paper was part of a doctoral study that was funded by the Faculty of Health and Life Sciences, Coventry University (United Kingdom).

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Article Citation

Durell, S. (2016). "Welcome to the real world" inclusive research with people with learning disabilities: A doctoral journey. *The Qualitative Report*, 21(12), 2308-2330. Retrieved from <http://nsuworks.nova.edu/tqr/vol21/iss12/9>
